

Background:

The Council periodically reviews TCDD's Position Statements. In August, the Council will review the Employment, Education, and Transition Position Statements. In November, the Council will review the Criminal Justice, Service Coordination, and Transportation Position Statements. This quarter, TCDD staff asked Council members to review and recommend updates for the following Position Statements: Aging with Developmental Disabilities, Access to Health Care, Community Living, and Right to Privacy.

The following Position Statement documents are included for your review:

- A. **Aging with Developmental Disabilities** – Current Position Statement with Markups*
- B. **Access to Health Care** – Current Position Statement with Markups*
- C. **Community Living** – Current Position Statement with Markups*
- D. **Right to Privacy** – Current Position Statement with Markups*

***PURPLE** Council Member input; **RED** Staff input

Public Policy Committee — Agenda Item 6
Expected Action:

The Public Policy Committee will consider changes to four position statements and recommend revisions to the Council.

Council — Agenda Item 7
Expected Action:

The Council will consider revisions to the TCDD Position Statements recommended by the Public Policy Committee and determine final action.

Aging with Developmental Disabilities

Position Statement

The Texas Council for Developmental Disabilities supports the position that all people aging with disabilities should be fully included in their communities. Many people with developmental disabilities are supported throughout their lives by family caregivers. The number of older adults with intellectual and developmental disabilities is expected to triple over the next twenty years and the majority of Texans waiting for services have a primary caregiver who is between 31 and 59 years of age.¹ As people with developmental disabilities and their caregivers' age, they have the right to continue to live in the community and exercise control over their own lives. ~~Each~~ All individuals faces challenges caused by the aging process and needs flexible services and supports ~~systems~~ equipped to meet their changing needs.

Therefore, the Council supports the position that Texas has a responsibility to ensure that the state's long-term services and supports system can meet the needs of older Texans with disabilities and their aging family caregivers by:

1. Ensuring that ~~long-term~~ services and supports are available and flexible enough to allow each aging individual to remain in their home and community and exercise control over their own lives.
2. Building expertise among service providers to assist people with developmental disabilities who are aging and their family caregivers in actively planning for their future long-term ~~care~~ services and supports needs.
3. Increasing capacity for respite services for aging caregivers of people with developmental disabilities.
4. Including people representing the disability community on any committee developing or reviewing initiatives and policies related to aging.
5. Assisting people to establish a comprehensive retirement plan to encompass any or all of the following concerns:
 - ~~access to~~ health care
 - ~~advanced~~ directives ~~relating to health care~~
 - counseling ~~services~~
 - retirement and/or employment ~~options~~
 - guardianship/alternatives to guardianship
 - housing
 - legal ~~issues~~
 - leisure time ~~activities~~
 - long-term services and supports plan
 - ~~financial issues~~ money
 - self advocacy ~~training~~
 - transportation

Texas leads the nation in promoting independence of people with disabilities and can continue to set the standard as its population ages.

Approved ~~May 9, 2014~~

¹ Texas Biennial Disability Report, Texas Council for Developmental Disabilities, 2010.

Access to Health Care

Position Statement

The Texas Council for Developmental Disabilities supports the position that all people, regardless of their disability, age, or ability to pay, should have access to affordable, comprehensive health care. ~~TCDD-The Council~~ supports healthcare initiatives and efforts to increase the access and affordability of health insurance for everyone.

The ~~Texas Council for Developmental Disabilities Council~~ supports the expansion of Medicaid for Texas under the federal Affordable Care Act. ~~The expansion would have covered an additional 1.2 million Texans by 2016. As a result, Texas has the biggest coverage gap in the country, with 766,000 residents ineligible for Medicaid and also ineligible for premium subsidies to offset the cost of private coverage in the exchange. We-The Council~~ supports the position that in any consideration of changes to the healthcare financing and delivery system in the United States, the well-being of the ~~patient individual~~ must be the highest priority. The Council strongly supports the reform measures and principles set forth in this statement as providing individuals consistent access to patient centered, timely, unencumbered, affordable and appropriate health care and universal coverage while maintaining physicians as an integral component to providing the highest quality treatment.

The Council supports the position that as policymakers consider healthcare reforms they should:

- Ensure ~~patients individuals~~ are empowered to control and decide how their own healthcare dollars are spent;
- Ensure unencumbered access to specialty care;
- Make healthcare coverage more affordable; ACA created a subsidy system for low and some middle income families to help purchase of insurance in the state insurance exchanges. The law sets a cap on the amount of insurance premium that individuals and families will to pay for the second cheapest Silver plan based upon that person/family's income in relation to on the Federal Poverty Level (FPL). These subsidies need to extend to individuals with developmental disabilities-IDD and not tied to FPL-not eligible for Medicaid.
- Improve value and increase quality ~~on in~~ our healthcare system;
- Extend both coverage and access ~~for to~~ the uninsured and under-insured;
- Avoid establishing new unsustainable programs;
- Provide comprehensive, culturally and linguistically appropriate behavioral and mental health services and supports;

- Provide services in the context of a patient centered medical home, where the clinician works in partnership with the individual and/or family to ensure that all ~~of the~~ medical and nonmedical needs of the person are met;
- Ensure ~~that~~ children and adults with behavioral and/or mental health concerns have access to screening, diagnosis and treatment that is not subject to arbitrary limits on coverage and integrated into the broader healthcare system;
- Ensure that people with disabilities of all ages and their families have access to health care that responds to their needs over their lifetimes, and provides continuity of care that helps treat and prevent chronic conditions;
- Ensure that people with disabilities and their families receive comprehensive health, rehabilitation, habilitation, and long term support services provided on the basis of individual need, preference, and choice;
- Ensure that people with disabilities and their families have equitable and affordable access to health coverage programs ~~and are~~ not ~~be~~ burdened with disproportionate costs.

The Council is concerned about proposals to block grant Medicaid because people with disabilities are especially vulnerable to reductions in Medicaid spending since they typically require more health services and long term supports. Reforms are necessary to strengthen the current Medicaid program so that it provides accessible, high-quality healthcare services to people with disabilities enrolled in the program; with changes that include, but are not limited to, evidence-based practices and payment structures that attract providers.

Community Living Position Statement

The Texas Council for Developmental Disabilities supports the position that individuals with disabilities should have access to opportunities and the supports needed to make their own decisions, be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, the state, and the nation.

Individuals with disabilities must have access to the full range of accommodations necessary to ensure that living in their community is possible. These accommodations may take various forms such as supported decision-making, personal attendant services, medication monitoring, respite, durable medical equipment, employment services, transportation, and/or minor home modifications. Accommodations may be sustained needed for either longer or shorter duration-time or may be of greater or lesser intensity-amount depending on the need of the individual.

Services to children should be provided in their family setting-home. When children cannot remain with their families, they must be cared for using principles, policies and processes akin to those of permanency planning and have access to family-based alternatives that ensure enduring-loving and nurturing relationships.

Adults with disabilities shall have choice and control about where, how, and with whom they live. They must be provided with assistance that may be needed, like supported decision-making, to make these choices and to sustain choices regarding community living. All people with disabilities should have access to the services and supports they need to live in the community. The state of Texas must allocate the requisite resources to support community living for people with disabilities. In addition, the state must rapidly expand the availability of individualized community options, transition all individuals in state institutions to community living, commit to a transition plan to close state supported living centers and transfer any cost savings to quality community programs. Communities must also be cultivated-helped to ensure-local-systems foster accessibility within and across all facets of community life, so that maintaining community placement is a feasible outcome for individuals with disabilities.

Right to Privacy

Position Statement

The Texas Council for Developmental Disabilities recognizes that people with disabilities have the same right to privacy as all people have in our nation. Confidentiality has historically been a cornerstone in providing services and medical care to people. The level of privacy protected under the Fourth Amendment of the U.S. Constitution is being challenged by the rapidly developing interactive technologies with a quickly emerging global information infrastructure.

In this age of the evolving information and communication technologies, the Council recognizes the positive role that the electronic media brings to the compilation and exchange of information. Our government agencies, businesses and non-profit agencies now have the advantage of quick exchange of information and the ability to gather and analyze massive amounts of information. This new capacity can help in streamlining business, reducing costs and ensuring appropriate services for people. However, this new capacity for data collection can also be used intentionally or unintentionally to the detriment of the people the government agencies serve. The Council supports the position that the following basic principles should be applied to all information data collection systems:

1. Individuals, government entities, nonprofit organizations, and businesses have a shared responsibility for the secure use of personal information.
2. Prior to the collection and dissemination of personal and identifiable information, each individual should be advised of:
 - a. The specifics of personal information to be collected and/or released;
 - b. The entity which is collecting the information and the entity to which the information will be released;
 - c. The purpose for which the information is to be collected and/or released;
 - d. The individual's legal rights to privacy and confidentiality of personal information;
 - e. The administrative procedures to follow to review personal information;
 - f. The process to remove, correct or add information that has been entered in a data collection system;
 - g. The avenues of recourse to recover damages in the case of improper use and/or disclosure of personal information; and
 - h. The degree of risk that personal information may be inadvertently collected by other entities through the electronic transmission processes.

3. Those who obtain, possess or retain personal information should make efforts to ensure that such personal information is not inadvertently shared, obtained, or collected by unauthorized parties through the process of electronic data transmission.
4. ~~Directories of a~~ An individual's personal information should be used only as allowed by the individual. Personal identifiable information may include:
5. basic identifying information, including name, address, telephone number, or email address;
6. social security number;
7. religious, political or organizational affiliations;
8. employment, educational, medical, psychiatric, psychological, and financial status,
9. legal history; and
10. family status.

Approved ~~November 7, 2014~~